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TITLE: Family Caregivers for Veterans with Spinal Cord Injury: Exploring the Stresses and Benefits.

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<b>13. SUPPLEMENTARY NOTES</b>											
<b>14. ABSTRACT</b> When family caregivers are unable to cope effectively with all role responsibilities, the health and well-being of the care recipient also may be jeopardized. Unfortunately, there are few studies that examine the intricacies of caregiving for people with spinal cord injuries. The purpose of this study is to identify issues specific to family caregivers of veterans with spinal cord injuries and develop a relevant, culturally appropriate instrument to assess caregiver distress and/or benefit. Family caregivers of veterans from three geographically diverse sites (Richmond, Virginia, Seattle, Washington, and Denver, Colorado) are being recruited to participate in focus groups discussing caregiving issues. To date, five focus groups with a total of 34 participants were completed in Richmond and two groups in Denver with a total of 8 participants. IRB approval in Seattle is still pending but in progress. It is anticipated that IRB approval will be finalized in Seattle within the month of October 2013 and focus groups will be convened before 2014 if possible.											
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<b>TABLE OF CONTENTS</b>	<b>PAGE</b>
Introduction.....	4
Body.....	5
Key Research Accomplishments.....	8
Reportable Outcomes.....	8
Conclusion.....	8
References.....	8
Appendices.....	None

## INTRODUCTION

**Background:** Spinal cord injury (SCI) often results in physical limitations such that receiving assistance from others is critical to maintaining health and facilitating full societal integration. In the general population, almost 70% of people with SCI receive some form of assistance and support from family members. Similarly, the availability of family caregiving is crucial to most veterans with SCI, but there is little research addressing the topic, and no appropriate and available method to comprehensively assess the strengths of and burdens on family caregivers. In the years following rehabilitation, people with SCI will have an increasing need for help as they age. With advancements in quality of care and the fact that the average age of all people living with SCI is over 45 and at least one-fourth have been injured for 20 or more years, the number of people with SCI who require home-based assistance will only increase in the coming years. This is particularly relevant for the veteran population, which is reported to be older, on average, than the general population of people with SCI.

**Research Problem:** When family caregivers are unable to cope effectively with all role responsibilities, the health and well-being of the care recipient also may be jeopardized. Ultimately, the inability to continue providing care because of declining physical or emotional health may lead to institutionalization of the care recipient. While institutionalization may be considered an acceptable option for frail elderly individuals who have numerous medical and cognitive impairments, people with SCI are likely to be younger and have many years of life ahead of them, and thus may find institutionalization unacceptable. Clearly, the health and well-being of the caregiver is an essential component that helps enable the person with SCI to function as independently as possible and participate in society. A qualitative approach takes advantage of the rich information provided by those living the experience of caregiving and SCI, enabling us to learn what matters most to these caregivers and can help inform the development of an instrument that is relevant to this unique population of family caregivers to veterans with SCI. In better assessing the issues facing family caregivers, we have the potential to address their health and emotional needs and thus positively impact the function, wellness and overall quality of life for veterans who have sustained SCI during or after their years of service.

**Specific Aims:** The goal of this project is to explicate the specific issues related to caregiving in SCI and develop a relevant and culturally appropriate instrument to assess caregiver distress and/or benefit in SCI. The development of an appropriate measurement tool will help clinicians and service providers better target their interventions, with the goal of improving the support system for veterans with SCI and their family caregivers, and thereby improving long-term outcomes for those veterans with SCI.

**Study Design:** The proposed will first entail a qualitative design that will involve focus groups of family caregivers of veterans with SCI drawn from three VA study sites. At least 5 focus groups of up to 7 participants at each site will be the minimum necessary to identify the relevant issues and themes. Audiotapes of the focus groups will be transcribed verbatim and analyzed using NVivo-8 qualitative analyses software. Coding will be conducted by three researchers to identify themes that will be used to design a relevant and culturally sensitive instrument to assess caregiver distress and benefit in SCI. Results of this study will be disseminated to relevant stakeholders via presentations and publications.

By the end of this study, the field will have definitive information about the issues facing caregiving family members to veterans with SC and will have a new instrument to assess SCI caregiver distress and benefit in this unique military population.

**Impact:** The proposed study has a high degree of relevance for veterans with SCI and their family members due to the current lack of information in this area. The knowledge gained from this research will inform clinicians as they work with families early during the SCI rehabilitation process and in the years beyond, enabling them to have a more relevant means of assessing SCI caregiving issues. Without an appropriate psychometrically sound measure of caregiving, the effectiveness of new interventions to help family caregivers cannot be assessed. The proposed qualitative and quantitative methods will provide that needed SCI-specific measure. Finally, we anticipate the study ultimately will benefit veterans with SCI themselves, as it has been noted that erosion in the health and well-being of the primary caregiver may lead to the development of expensive and preventable secondary complications in the person with SCI.

## BODY

### Objective 1 – Identify participants and conduct focus groups/interviews 1-36)

Task	Activities	Months	Status
1a:	Schedule and conduct collaborator teleconferences and local project site team meetings.	1-36	Completed
1b:	Obtain IRB approval from each study site	1-6	Received from Richmond and Denver, still waiting on IRB approval from Seattle. Personnel changes in Seattle have delayed this process but as of September 2013 IRB approval is expected within 30 days UPDATE: Notified by Seattle that the IRB is understaffed and not approving outside projects at this time. Seattle has withdrawn from the study.
1c:	Identify study subjects	6-12	Richmond – completed Denver – completed
1d:	Mail invitations to potential participants - A letter to the individual with SCI will explain the purpose of the study and ask them to nominate one family member who provides personal assistance to them. Identified individuals will be invited to participate in a focus group to discuss his or her caregiving experiences. Participants will receive \$60.00 to thank them for their time and compensate travel	6-12	Richmond – completed Denver – completed
1e:	Update literature review – the existing	1-12	Completed

	literature review used to prepare this proposal will be updated quarterly during the first year of the project to identify any new information and themes regarding caregiving		
1f:	Conduct focus groups/interviews - The PI (Charlifue) will lead each focus group at all sites along with a local facilitator	7-15	Richmond – completed Denver – 2 groups have been completed; anticipate 2 more groups to be scheduled UPDATE – no further word from Denver regarding additional groups
1g:	Identify missing topics on existing caregiver instrument (CBI, described in Project Narrative)	7-15	To be completed when all focus groups convened and transcripts analyzed

#### **Objective 2 – Analyze qualitative data**

Task	Activities	Months	Status
2a:	Transcribe audiotaped sessions	7-18	Richmond being done currently – UPDATE – transcription of all Richmond and both Denver groups completed
2b:	Export data to NVivo 8	7-18	Pending completion of transcription UPDATE – in progress
2c:	Perform qualitative analysis - Qualitative ongoing analysis of focus group and individual interviews by the PI and two Research Assistants at Craig Hospital	7-21	Pending completion of 2b UPDATE – in progress
2d:	Maintain codebook to document the coding criteria for particular thematic codes and document the sequence of analysis decisions	1-21	Pending completion of 2b UPDATE – in progress

#### **Objective 3: Develop a relevant and culturally sensitive instrument to assess caregiver distress and/or benefit in SCI:**

Task	Activities	Months	Status
3a:	Identify and operationalize themes/topics	7-24	
3b:	Review of questions by focus group participants questions. This will be performed by mailing a packet with the first draft of the questionnaire as well as a stamped return envelope with instructions to rate the questions on importance, relevance, and cultural applicability. Participants will receive \$20.00 to thank them for their input	21-24	Pending completion of 2b UPDATE only those questions unique to the veteran caregiver group will need to undergo additional review by participants.
3c:	Refine questions and develop pilot instrument	21-24	Partially completed; additional questions to be added after all focus

			groups completed UPDATE – will use same questions as developed in civilian caregiver study where themes are the same as with the veteran caregivers. New questions will be limited to themes exclusive to veteran caregivers (anticipate few)
3d:	Cognitive testing of the proposed questions. The cognitive interviews will be administered either in person or by telephone by the Craig team. Individuals will be paid \$25.00 for their participation in the cognitive interviews	25-27	Not yet scheduled to start UPDATE – will be done after 3c completed
3e:	Revise questions based on cognitive testing and finalize first draft	25-27	Not yet scheduled to start UPDATE – will be done after 3d completed

**Objective 4: Conduct pilot test of newly developed instrument**

Task	Activities	Months	Status
4a:	Pilot test instrument. Participants will be asked to review and sign a newly approved consent form (submitted by each site to their respective IRB), complete the questionnaire and return it to the site Co-Investigator (then forwarded to the PI) in a provided stamped return envelope. A \$7.00 check will be included in the mailing as a “thank you” to participants	25-30	Not yet scheduled to start
4b:	Enter and clean pilot test data - Data from the pilot testing will be entered into a Microsoft Access® database and checked for accuracy using a 10% quality control sample. Any discrepancies noted in the 10% sample will necessitate full double entry of all data to ensure full accuracy	27-30	Not yet scheduled to start
4c:	Analyze pilot test data	30-33	Not yet scheduled to start
4d:	Prepare final caregiver assessment instrument. Based on the analysis in 4c above, a final draft of a SCI caregiver assessment instrument will be prepared for a validation study in a future project	34-36	Not yet scheduled to start

**Objective 5: Dissemination**

5a:	Prepare manuscript of qualitative findings	27-36	Not yet scheduled to start
5b:	Presentations at professional meetings	18-24 and 30-36	Presentation at State of the Science conference on Families of Injured, Ill and Wounded Veterans, September 2013

**ADDITIONAL INFORMATION:** The VA sites required that the PI (Charlifue) have a WOC in order to conduct the focus groups on site. Acquisition of the WOC took approximately 10 months to obtain and focus groups had to be postponed until the WOC was in hand.

UPDATE – due to delays in IRB approvals (and in some cases, inability to obtain IRB approval) a contingency plan to move forward with data from the 7 existing focus groups was discussed with project officer.

**KEY RESEARCH ACCOMPLISHMENTS**

No key research accomplishments to report as of yet other than the objectives achieved as noted above.

UPDATE – 7 focus groups completed (5 in Richmond, 2 in Denver). 41 participants; mean age 59 years, 95% female; 51% Caucasian; 78% spouse; mean years of caregiving 11.8 (range <1-52); mean hours per day caregiving 9.9. Themes appear similar to those identified in a study of civilian caregivers with some positives noted, outweighed by negatives. Positive themes include change in self-awareness, closeness of family, increased compassion, feeling appreciated, still having family member with them. Negatives include lack of time for self, physical and emotional exhaustion, lack of spontaneity, lack of understanding from others, lack of appreciation from family members, unexpected illnesses, dissatisfaction with hired carers and agencies, strain on family relationships. Caregivers also report changes in work (ability to maintain jobs or need to reduce hours), finances, limited travel and leisure, lack of privacy, loss of friendships.

**REPORTABLE OUTCOMES**

No reportable outcomes as of yet.

**CONCLUSIONS**

No conclusions to report as of yet.

**REFERENCES**

None

**APPENDICES**

None